

# Seacoast Cancer Cluster Investigation Questionnaire



## Introduction

Thank you for agreeing to participate by taking this questionnaire. The New Hampshire Department of Health and Human Services (DHHS) is investigating cases of pediatric rhabdomyosarcoma (RMS) and pleuropulmonary blastoma (PPB) among individuals who were diagnosed with one of these types of cancer on or after January 1, 2001 at age 19 or younger who have spent a substantial amount of time in the seacoast area of New Hampshire.

Research shows that there are no clear risk factors or environmental exposures associated with RMS or PPB, but we are investigating in order to try to identify a possible explanation for the cluster. We are asking parents or guardians of affected children to provide detail about their child’s diagnosis, medical history, and possible exposures experienced by their children.

This questionnaire should take between 15 and 30 minutes to complete. Please respond to each question by either providing the detail requested or selecting (**circling**) your response. If you have any questions or concerns about the survey, please call us at 603-271-1568. **Once you have completed the questionnaire, please return it to DHHS in the envelope provided.**

## Interviewee Information

1. What is your name? \_\_\_\_\_
2. What is the best phone number to contact you? \_\_\_\_\_
3. What is your email address: \_\_\_\_\_
4. What is the best way to contact you if we have questions or need clarification? \_\_\_\_\_
5. What is your relationship to the child? \_\_\_\_\_

## Child information

6. Child’s name \_\_\_\_\_
7. Child’s date of birth \_\_\_\_\_
8. Is child adopted?
  - a. Yes
  - b. No
  - c. Don’t know/not sure
9. Child’s sex
  - a. Female
  - b. Male
  - c. Other (*specify*: \_\_\_\_\_)
10. Child’s vital status
  - a. Living
  - b. Deceased

11. Child's race:
- a. Asian
  - b. Native Hawaiian/Other Pacific Islander
  - c. Black/African American
  - d. American Indian/Alaska Native
  - e. White
  - f. More than one race
  - g. Other (*specify*: \_\_\_\_\_)
12. Child's ethnicity
- a. Hispanic
  - b. non-Hispanic
13. Child's age at diagnosis of RMS or PPB (years, or months if child was under age 1) \_\_\_\_\_
14. Date of diagnosis (month/year) \_\_\_\_\_
15. Names of physician(s) and facility where the child was first diagnosed.
- a. Physician: \_\_\_\_\_
  - b. Facility: \_\_\_\_\_
  - c. If needed, may we contact this person?
    - a. Yes
    - b. No
16. Approximate date when child first developed symptoms (month/year) \_\_\_\_\_
17. Location/anatomical site of primary tumor \_\_\_\_\_
18. Type of diagnosis (*circle all that apply*)
- a. Alveolar rhabdomyosarcoma (RMS)
  - b. Embryonal RMS
  - c. Pleuropulmonary blastoma (PPB)
  - d. Other (*specify*: \_\_\_\_\_)
  - e. Don't know/not sure

## Residence and School Locations

19. Where did your child live **when he or she was diagnosed with RMS or PPB?**

Street address (do not use a PO Box number)	City	State	ZIP code	Dates lived in residence (month/year to month/year)

20. Did your child live anywhere else **before he or she was diagnosed with RMS or PPB**?
- Yes (complete table below)
  - No (go to question #21)
  - Don't know/not sure (go to question #21)

	Street address (do not use a PO Box number)	City	State	ZIP code	Dates lived in residence (month/year to month/year)
A					
B					
C					

Add additional letters and information below for any additional residences

21. List schools or childcare facilities that your child attended **before being diagnosed with RMS or PPB** (if they did not attend child care or school, leave blank and go to question #22).

	Name of school or childcare center	Street address (do not use a PO Box number)	City	State	ZIP code	Dates of attendance (month/year to month/year)
A						
B						
C						
D						
E						

Add additional letters and information below for any additional schools or childcare facilities

22. Did your child spend at least 28 days cumulatively at any location in NH other than the residences or schools mentioned above **before being diagnosed with RMS or PPB**, such as time at summer camps or visiting family?
- Yes (complete table below)
  - No (go to Question #23)
  - Don't know/not sure (go to Question #23)

Location type (relative, summer camp, vacation home, etc.)	Street address (do not use a PO Box number)	City	State	ZIP code	Dates spent at location (month/year to month/year)
A					
B					
C					
D					

23. Is there any other location not already mentioned that you believe your child spent substantial time **before the diagnosis of RMS or PPB**?
- Yes (complete table below)
  - No (go to Question #24)
  - Don't know/not sure (go to Question #24)

Location Name /Type	Street address (do not use a PO Box number)	City	State	ZIP code	Dates (month/year to month/year)
A					
B					
C					

## Child's Medical History

24. List any history of disease or illness, other than RMS or PPB, that the child has now or had in the past which was diagnosed by a healthcare provider (if none, write "None" in row A and go to question #25):

Disease or Illness	Date of Onset (month/year)
A	
B	
C	
D	
E	

25. List any medication that has been taken by the child (include prescriptions, over the counter medications, and supplements) (if none, write "None" in row A and go to question #26):

Medication Name	Reason for Medication	Date(s) taken (month/year)
A		
B		
C		
D		
E		

26. Did the child ever smoke or chew tobacco on a regular basis **before being diagnosed with RMS or PPB?**

- Yes
- No
- Don't know/not sure

27. **Before diagnosis**, did the child ever use recreational drugs?

- Yes (if yes, which drugs? \_\_\_\_\_)
- No
- Don't know/not sure

28. Did the child have any birth defects or syndromes including the following:
- Beckwith-Wiedemann syndrome (*a condition that is classified as an overgrowth syndrome*)
  - Costello syndrome (*a condition characterized by delayed development and intellectual disability, loose folds of skin, unusually flexible joints, and distinctive facial features*)
  - Li-Fraumeni syndrome (*an inherited disease characterized by soft tissue sarcomas, osteosarcomas, early-onset breast cancer, adrenal cancers, brain tumors, and leukemia*)
  - Neurofibromatosis type 1 (*also called Recklinghaus disease, a genetic disorder that causes tumors to grow in the nervous system*)
  - Noonan syndrome (*a condition characterized by distinctive facial features, short stature, heart defects, bleeding problems, skeletal malformations, and other signs and symptoms*)
  - Other: Specify \_\_\_\_\_
  - None
29. Did the child **ever** receive any genetic testing, including after being diagnosed with RMS or PPB?
- Yes
  - No (Go to Question #31)
  - Don't know/not sure (Go to Question #31)
30. If yes, may we contact you to discuss the findings of the genetic tests?
- Yes
  - No
  - Don't know/not sure
31. **Before your child displayed the symptoms that led to the cancer diagnosis**, did he/she ever receive an x-ray or CT ("CAT") scan or participate in a nuclear medical study (a nuclear medical study uses radioactive materials to assess function of organs (thyroid, bones, heart, liver, etc...))?
- Yes
  - No (go to Question #33)
  - Don't know/not sure (go to Question #33)
32. If yes, specify type, month/year given, exposure location on the body, and reason x-ray or scan given.
- X-ray      month/year: \_\_\_\_\_      body location: \_\_\_\_\_      reason: \_\_\_\_\_
  - CT scan      month/year: \_\_\_\_\_      body location: \_\_\_\_\_      reason: \_\_\_\_\_
  - PET scan      month/year: \_\_\_\_\_      body location: \_\_\_\_\_      reason: \_\_\_\_\_
  - SPECT scan      month/year: \_\_\_\_\_      body location: \_\_\_\_\_      reason: \_\_\_\_\_
  - Other scan      month/year: \_\_\_\_\_      body location: \_\_\_\_\_      reason: \_\_\_\_\_
33. **Before your child displayed the symptoms that led to the cancer diagnosis**, did the child ever receive radiation therapy for any illness, such as radiologic treatment for a different type of cancer?
- Yes (Specify reason: \_\_\_\_\_ Date (month/year) \_\_\_\_\_)
  - No
  - Don't know/not sure

## Prenatal History

**Note that prenatal history questions are referencing when the biological mother was pregnant with the child who was later diagnosed with RMS or PPB.**

34. Where did the biological mother live **when she was pregnant?**

Street address (do not use a PO Box number)	City	State	ZIP code	Dates lived in residence (month/year to month/year)

35. Did the biological mother primarily use well water or public water for drinking and cooking **while pregnant?**

- a. Well water
- b. Public water
- c. Both well and public water
- d. Don't know/not sure

36. **During pregnancy**, did the biological mother take any medications (including both chronic medications, and short-term medications such as antibiotics; include supplements, OTCs, vitamins, and herbal medicines)?

- a. Yes (complete the table below)
- b. No (go to question #38)
- c. Don't know/not sure (go to question #38)

Medication name	Reason for Medication	Date(s) taken (month/year)
A		
B		
C		
D		

37. Did the biological mother smoke tobacco products **during pregnancy?**

- a. Yes
- b. No (go to Question #40)
- c. Don't know/not sure (go to Question #40)

38. How many packs per day of cigarettes did the biological mother smoke?

- a. Number packs per day: \_\_\_\_\_
- b. If smoked other tobacco product, specify: \_\_\_\_\_

39. Did the mother smoke tobacco products **after the child was born but before the RMS diagnosis?**

- a. Yes
- b. No (go to Question #42)
- c. Don't know/not sure (go to Question #42)

40. How many packs per day of cigarettes did the mother smoke?
- Number packs per day: \_\_\_\_\_
  - If smoked Other tobacco product, specify: \_\_\_\_\_
41. **During pregnancy**, did the biological mother use any recreational drugs such as cocaine, marijuana, heroin, etc?
- Yes
  - No (go to question #43)
  - Don't know/not sure (go to question #43)
42. Which of the following drugs did the biological mother use? (Circle all that apply and include detail about frequency—daily, weekly, monthly; and duration- number of months or years.)
- Cocaine frequency: \_\_\_\_\_, duration \_\_\_\_\_
  - Heroin frequency: \_\_\_\_\_, duration \_\_\_\_\_
  - Marijuana frequency: \_\_\_\_\_, duration \_\_\_\_\_
  - Other (specify type, frequency, and duration: \_\_\_\_\_)
43. Did any other person in the household besides the child's mother smoke **while the mother was pregnant**?
- Yes
  - No
  - Don't know/not sure
44. Did any other person who spent time with the child smoke **after the child was born, but before the child was diagnosed with RMS or PPB**?
- Yes
  - No
  - Don't know/not sure
45. How old was the biological mother when the child was born? \_\_\_\_\_ (years)
46. How old was the biological father when the child was born? \_\_\_\_\_ (years)
47. **During pregnancy**, did the biological mother have anemia (anemia is defined as a low red blood cell count, which would be diagnosed by a blood test and might sometimes be treated with iron or in severe cases, by a blood transfusion)?
- Yes
  - No
  - Don't know/not sure
48. **During pregnancy**, was the mother exposed to x-rays, including from CT scans, or was the mother exposed to radiation from a nuclear study? Examples include dental x-rays, chest x-ray, mammogram, CT scan of the abdomen, PET and SPECT scans. Do not include ultrasounds or MRIs.
- Yes
  - No (go to question #50)
  - Don't know/not sure (go to question #50)

49. If yes, specify type, trimester given, exposure location on the body, and reason x-ray or scan given.

- a. X-ray      trimester: \_\_\_\_\_ body location: \_\_\_\_\_ reason: \_\_\_\_\_
- b. CT scan      trimester: \_\_\_\_\_ body location: \_\_\_\_\_ reason: \_\_\_\_\_
- c. PET scan      trimester: \_\_\_\_\_ body location: \_\_\_\_\_ reason: \_\_\_\_\_
- d. SPECT scan      trimester: \_\_\_\_\_ body location: \_\_\_\_\_ reason: \_\_\_\_\_
- e. Other scan      trimester: \_\_\_\_\_ body location: \_\_\_\_\_ reason: \_\_\_\_\_

50. **During pregnancy**, did the biological mother experience any abnormal vaginal bleeding?

- a. Yes
- b. No
- c. Don't know/not sure

51. **During pregnancy**, did the biological mother experience any other complications?

- a. Yes
- b. No (go to question #53)
- c. Don't know/not sure (go to Question #53)

52. Describe other pregnancy complications (include detail about when they occurred):

53. What was your child's weight at birth (lbs and oz)? \_\_\_\_\_ lbs \_\_\_\_\_ oz

54. At what gestational age (in weeks) was the child born?

- a. \_\_\_\_\_ (in weeks)
- b. Don't know/not sure

## Family Health History

55. Has any close relative of the child (parent, sibling, aunt/uncle, cousin, grandparent) been diagnosed with any cancer? Examples include breast cancer, leukemia, brain cancer, or other types.
- Yes (complete table below)
  - No (go to Question #56)
  - Don't know/not sure (go to Question #56)

Relationship to child	Cancer type	Primary site of cancer	Blood relative (yes/no/unsure)	Age at Diagnosis (years)
A				
B				
C				

56. Has any close relative (parent, sibling, aunt/uncle, cousin, grandparent) been diagnosed with any of the following genetic disorders or syndromes (see question 28 for descriptions):

- Beckwith-Wiedemann syndrome
- Costello syndrome
- Li-Fraumeni syndrome
- Neurofibromatosis type 1
- Noonan syndrome
- Other: Specify \_\_\_\_\_
- None

57. Has any close relative (parent, sibling, aunt/uncle, cousin, grandparent) been diagnosed with the genetic mutation called DICER1?

- Yes
- No
- Don't know/not sure

58. Has any close relative (parent, sibling, aunt/uncle, cousin, grandparent) been diagnosed with any other genetic mutation?

- Yes
- No (go to question #60)
- Don't know/not sure (go to question #60)

59. If yes, may we contact you to discuss the genetic mutation?

- Yes
- No

## Occupational History

60. **When the child was diagnosed with RMS or PPB**, what kind of business or industry did the father work in (for example, hospital, elementary school, restaurant, clothing manufacturing)? *(if manufacturing, indicate type; if father was unemployed, write "unemployed")*

---

61. What was his job or position? \_\_\_\_\_

62. Dates worked in that position (month/year to month/year) \_\_\_\_\_

63. Did the father have any known chemical or radiologic exposures at work?

- a. Yes
- b. No (go to question #65)
- c. Don't know/not sure (go to question #65)

64. If yes, provide detail about type(s) of exposure(s) (including types of chemicals, if known):

65. Did the father have any other jobs **before the child was diagnosed but after conception**?

- a. Yes (complete table below)
- b. No (go to question # 66)
- c. Don't know/not sure (go to question # 66)

Work Type/Industry	Job Title	Start & End Dates (Month/Year)	Any chemical or radiologic exposures? Yes/No/Don't know (if yes, specify)
A			
B			
C			

66. **When the child was diagnosed with RMS or PPB**, what kind of business or industry did the mother work in (for example, hospital, elementary school, restaurant, clothing manufacturing)? *(if manufacturing, indicate type; if father was unemployed, write "unemployed")*

---

67. What was her job or position? \_\_\_\_\_

68. Dates worked in that position (month/year to month/year) \_\_\_\_\_

69. Did the mother have any known chemical or radiologic exposures at work?

- a. Yes
- b. No (go to question #71)
- c. Don't know/not sure (go to question #71)

70. If yes, provide detail about type(s) of exposure(s) (including types of chemicals, if known):

71. Did the mother have any other jobs **before the child was diagnosed but after conception**?

- a. Yes (complete table below)
- b. No (go to question #72)
- c. Don't know/not sure (go to question #72)

Work Type/Industry	Job Title	Start & End Dates (Month/Year)	Any chemical or radiologic exposures? Yes/No/Don't know (if yes, specify)
A			
B			
C			

72. Did the child have a job **before being diagnosed with RMS or PPB** (include part time jobs)?

- a. Yes (complete table below)
- b. No (go to question #72)
- c. Don't know/not sure (go to question #72)

Work Type/Industry	Job Title	Years Worked	Any chemical or radiologic exposures? Yes/No/Don't know (if yes, specify)
A			
B			
C			

### Other Potential Risk Factors

73. **Before the child was diagnosed with RMS or PPB**, did either parent have hobbies where chemicals were used? (examples film photography, furniture staining, gardening, working with metal, autobody work)
- Yes (complete table below)
  - No (go to question #74)
  - Don't know/not sure (go to question #74)

Please provide detail about products used:

Product Type		Product Brand
A		
B		
C		
D		

74. Before the child was diagnosed with **RMS or PPB**, what were the child's hobbies?

75. **Before the child was diagnosed**, did the child have any hobbies in which chemicals were used?
- Yes (complete table below)
  - No (go to question #76)
  - Don't know/not sure (go to question #76)

Please provide detail about products used:

Product Type		Product Brand
A		
B		
C		
D		

76. **Before diagnosis**, what type of water did the child primarily use (include water consumed at school and at home)?
- Public water
  - Well water
  - Both public and well water
  - Don't know/not sure

77. At any of the homes that the child lived in **before diagnosis or that the biological mother lived in while pregnant**, was the water ever tested for contaminants? (*common tests include those for arsenic, bacteria, chloride, copper, fluoride, hardness, iron, lead manganese, nitrate/nitrite, pH, sodium, uranium, analytical gross alpha, radon, and volatile organic compounds*)
- Yes (complete table below)
  - No (go to question #78)
  - Don't know/not sure (go to question #78)

Address of Residence (Street Address, City, State)	Test Date (month/year)	Results
A		
B		
C		

78. At any of the homes that the child lived in **before diagnosis or that the biological mother lived in while pregnant**, was the air ever tested for radon?
- Yes (complete table below)
  - No (go to question #79)
  - Don't know/not sure (go to question #79)

Address of Residence (Street Address, City, State)	Test Date (month/year)	Results
A		
B		
C		

79. Did the child live within 10 miles of any known hazardous or toxic waste sites, leaking underground storage tanks, chemical plants, waste incinerators or landfills **before being diagnosed with RMS or PPB?**
- Yes (complete table below)
  - No (go to question #80)
  - Don't know/not sure (go to question #80)

Address of Residence (Street Address, City, State)	Location (city, state)	Known hazardous or toxic waste type? (specify)
A		
B		
C		

80. Are there any other details or potential exposures that you think might help with this investigation? If so, please provide detail below (locations that the child spent time, exposures that the child might have experienced, etc.).

## Conclusion

Thank you for taking the time to answer these questions and helping us in this investigation. If we have any questions or need further clarification about your responses, we will reach you using the contact information provided to us. If you think of any other information that might be helpful, please contact us at 603-271-1568. Thank you again for your time.

**Please use the envelope provided to return this questionnaire to the Department of Health and Human Services at your earliest convenience.**